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ABSTRACT

Designed for the citizen advocate, the third in a series of four booklets provides basic information on mental retardation and the advocate's role. Reviewed is the history of social attitudes regarding the retarded, and described are the needs of institutinalized and community-living retarded persons. Discussed are emotional, legal, and financial considerations of being an advocate, and suggested are guidelines for protecting the protege's rights. Phases in the typical advocate-protege relationship are analyzed. Appended is the declaration of general and special rights of the mentally retarded developed by the International League of Societies for the Mentally Handicapped. (CL)

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Effective Advocacy

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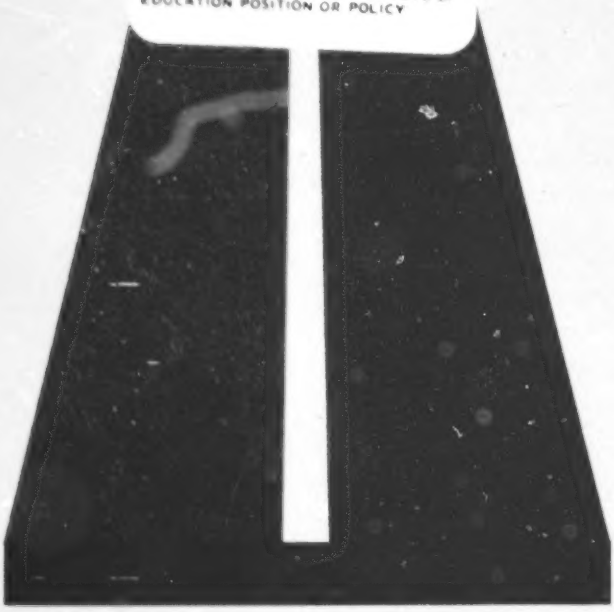

Avenues To Change

Book III

2

EC 081116

EFFECTIVE ADVOCACY

BOOK III

This series of materials was developed in conjunction with the NARC Project **A National Citizen Advocacy Model for Mentally Retarded Children,** Grant #OEG-0-72-5311, which was supported jointly by the Bureau of Education for the Handicapped, National Institute of Mental Health, and Rehabilitation Services Administration of the United States Department of Health, Education, and Welfare.

National Association for Retarded Citizens
February, 1974

PREFACE: BOOK III

Book III, **Effective Advocacy,** is designed especially for you, the advocate. It is the goal of this material to take the concern which has led you into the advocacy program, and provide you with the awareness and knowledge you need in order to turn this concern into effective action. Included are facts about mental retardation, examples of advocacy functions, descriptions of various phases in the advocate-protege relationship, and guidelines for ensuring the rights of mentally retarded persons.

This manual is part of a four-book set developed by the National Association for Retarded Citizens, and was written primarily to fill a gap in existing materials on advocacy by giving you some idea of what you can expect and what is expected of you as you become involved in the Citizen Advocacy program. After you have carefully studied this resource and Book I, **Citizen Advocacy for Mentally Retarded Children: An Introduction,** you should feel confident and informed about your role as an advocate. Facts are contained in Book III which have never been compiled in quite the same fashion before, and the material presented is especially slanted toward the advocate's viewpoint. You may also wish to read Book II which was written for advocacy coordinators and Book IV which was prepared for youth advocates.

It is the hope of NARC's Child Advocacy Project staff that Book III will serve you both as a training tool for advocates and a ready resource throughout your relationship with your protege. With the help of this book and the guidance and support of your state and local advocacy offices, coordinators, and advisory committees, you can make your unique advocacy relationship as rewarding as possible for both you and your protege.

BOOK III

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We are standing in a large room, about 60 feet by 50 feet in size. The walls are covered with hospital-style gray tiles, and the windows are formed from squares of almost opaque glass which permit only dull light to filter into the room and do not give a view of the outside world. The floor is terrazzo, and along the sides of the room are a half dozen wooden benches. There are no other furnishings. In the exact center of the floor, a drain opens into blackness, making it easy to hose down the tile when the day is over. Scattered around the room are some 50 mentally retarded people who alternately sit, stand, lie, huddle, pace, laugh, cry, or remain absolutely still. Some wear little clothing — some are old and some are young — some sit on benches while others crouch on the floor.

In the far corner, a little girl sits silently, hugging her shoulders and rocking back and forth. Her name is Anne, and she is severely retarded. A uniformed attendant walks over to her, bends down and says something to which there is no response, stands up and goes away again. When the attendant is halfway across the room, Anne looks up wearily at her retreating back, and then bows her head to resume her rocking.

This is a Day Room in a wing for severely and profoundly retarded residents in an institutional facility. Many institutions have far better conditions; others are worse. Outside the sun is shining on people going about their daily business, giving little thought to what is going on behind the walls and locked doors. However, some of these citizens **are** concerned; and better still, some of them actively want to help, but they don't know how, or who to ask, or where to go to find out. How can a link be formed between those inside institutions like Anne and those who want to reach them, to be their friends, and to act as spokesmen for their rights that are often denied to them? The answer in your community could be Citizen Advocacy.

* * *

We are now standing in the doorway of a small garage apartment in the suburbs of your city. It is sparsely equipped and carefully tended, and all of the furnishings seem to center around the portable television set situated on a table in the middle of the living room. A moderately retarded young man, named Alan, aged 19, lives here, alone. He has spent most of his life in an institution, but just recently has been able to move out on his own into the community. He currently holds down a job at a nearby theatre where he works as an usher, and he takes great pride each Friday in banking part of his salary. Alan has learned many things about your city already like how to use public transportation, but he needs someone to show him how to do other things like shopping for groceries or buying clothes. He would like to learn how to drive a car or a motorcycle, but there is no

one to instruct him. He is friendly during working hours with the theatre personnel, and he often enjoys watching some of the films on quiet nights. He also gets along well with the elderly lady who rents the apartment to him and has brought in firewood for her, and later enjoyed a neighborly cup of hot chocolate beside the fire they built. But when it comes to leisure-time activities, he is always alone. Sometimes he walks and walks for miles — alone. He feels that his associates at work know he is somehow "different", and he longs for just one person he can really call a friend . . . someone who can take him to new places . . . someone who can teach him how to ride a cycle . . . a young man his own age who he could talk to about girls and dating. Alan is shy around females and needs somebody to show him how to act on a date. Just now he walks to the window and looks out, ignoring the tiny, florescent figures on the TV screen. His own reflection stares back at him from the darkened windowpane, and he waits. How can he meet a friend — someone to give him companionship and guidance? The answer in your community could be a Citizen Advocate.

* * *

Now we are standing in front of an expensive split-level home in the "best part of town". Inside lives a 16-year-old girl named Marie who is mildly retarded, but also suffers from cerebral palsy. Marie's parents are divorced, and her mother works as a commercial artist for a large business firm. Marie has an older brother who is married and an 18-year-old sister who is a freshman in college. Although she is surrounded by a busy, loving family and is able to attend a special school where she has many friends with problems similar to hers, Marie longs for a "normal" friend her own age . . . a friend who knows all about fashion and hairdos, and rock music and movie stars and boys . . . a friend who has time to come by and take her riding sometimes and who can call her on the telephone at night.

Two streets over lives a 17-year-old girl named Annette who has her own car, works part-time after school in a boutique at a nearby shopping center, and knows all about the latest styles and fads. Annette is thinking about majoring in special education when she goes away to college next fall, and she is very interested in coming to know a handicapped person firsthand. How can these girls be matched? The answer in your community could be a local Citizen Advocacy office.

* * *

All of these cases are examples of the wide range of possibilities for relationships in a Citizen Advocacy program. Further reading of this book will reveal how both informal and formal advocacy relationships come into being, how an advocate can be the most effective in whichever role he chooses, what the advocate can ex-

pect in his relationship with a protege, and what is expected of him in return, and what risks and rewards are involved in being an advocate. It is hoped that through reading this book, the interested citizen can reach a stage of solid commitment to the program, or that the volunteer already in training will be able to strengthen his effectiveness in the time to come.

BASICS OF MENTAL RETARDATION

> **"To be conscious that you are ignorant is a great step to knowledge."**
>
> **Benjamin Disraeli**

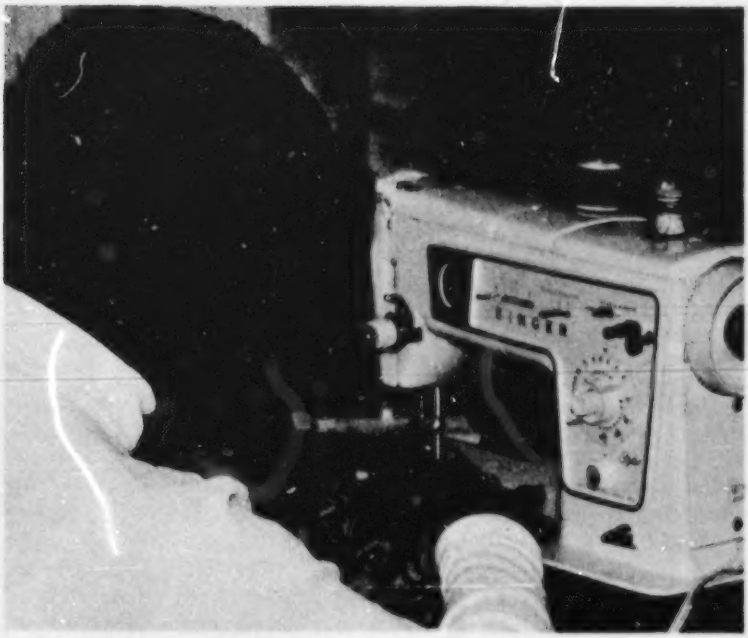
While many readers of this book will probably be familiar with mental retardation through personal experience or ARC affiliation, others will be coming into the program with little or no knowledge of facts and myths about retarded people. Therefore, a simple definition of mental retardation is the most logical place to begin. A definition which is generally accepted today in the United States was adopted by the American Association on Mental Deficiency (AAMD) in 1973, and was presented that year in its **Manual on Terminology and Classification in Mental Retardation.** This definition states that:

> **"Mental retardation refers to significant sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period."**

The terms used in this definition can be explained as follows:

> **SUB-AVERAGE GENERAL 'NTELLECTUAL FUNCTIONING: Falling below 97% of the population on standardized tests of global intelligence (tests which attempt to measure vocabulary, comprehension, memory, reasoning, judgment, and visual-motor functions).**
>
> **ADAPTIVE BEHAVIOR: The ability to adapt to and control one's environment, usually defined in terms of maturation, learning and social skills.**
>
> **DEVELOPMENTAL PERIOD: The period from conception to about 16 years of age.**

Mental retardation covers a broad spectrum of problems and causes, and is defined in terms of reduced intellectual functioning which, in turn, goes hand in hand with inadequacies in the areas of learning, applying knowledge, and relating to others. While the AAMD definition does not emphasize the limitations of mental retardation, it also does not sufficiently stress the growth poten-



tials of retarded persons. In simplest terms, mentally retarded individuals are slow or limited in their learning processes, and may not be able to readily apply what they learn to daily living, but they **can** develop at their own pace if helped to do so.

It is important to remember that "mental illness" is not synonymous with "mental retardation". Mental illness is different in that it concerns an inability to cope with one's environment regardless of intellectual level. Mental illness can occur at any stage of life while mental retardation is considered to be a developmental disability, beginning in the early years.

It is currently estimated that three percent of the population of the United States will at some time in their life function in the mentally retarded range. Therefore, six million Americans will fall within this group. However, **probably** no more than one percent of the population, or two million Americans, are actually classified as mentally retarded at any given time (Tarjan, 1973). The difference in percentages is mainly due to the fact that many children are not identified as mentally retarded until they reach school-age, and others will lose the label in adulthood.

Slightly more than 100,000 of the babies born each year are likely to be mentally retarded; and so by 1980, due to normal population growth, there will be almost an additional one million

mentally retarded individuals in this country (NARC's **Facts on Mental Retardation,** 1973).

Recent figures as presented in Table I below indicate that approximately 2.4 million of the total population of mentally retarded people are under 21 years of age, and are thus technically considered as children. According to further estimates, of this group, 2.1 million are mildly retarded; 144,000 are moderately retarded; 84,000 are severely retarded; and 36,000 are profoundly retarded. Figures representing members of these groups who are over 21 years of age are also included in Table I.

TABLE I

Estimated Numbers of Mentally Retarded Persons by Age and Degree

Degree of Retardation	Age of Retarded Persons	
	Under 21	Over 21
Mild	2,100,000	3,300,000
Moderate	144,000	222,000
Severe	84,000	130,000
Profound	36,000	56,000
Total	2,364,000	3,708,000

NOTE: Table I adapted from NARC's **Facts on Mental Retardation,** p.6, 1973.

Although the present trend is against "labeling" or strict categorization of mentally retarded persons, there are widely accepted terms for differentiating between the various degrees of mental retardation — "mild", "moderate", "severe", and "profound". In discussing these terms, it is important to remember that overzealous efforts to "pigeonhole" people can lead to mis-classification and do lifelong damage to the developmental potential of retarded persons.

Mildly retarded persons. As indicated above, this group comprises the majority (approximately 89 percent) of all mentally retarded persons. Many of this group are not identified before reaching school age since their impairments may not be conspicuous until they are placed in a school setting. Some will be placed in special education classes. Others may continue, with difficulties, for some time in regular classes. With proper education and training, by adulthood almost all mildly retarded persons can be prepared to live and work independently with occasional assistance or counseling in social, financial, and possibly, legal matters.

Moderately retarded persons. This group constitutes approximately 6 percent of all mentally retarded persons. They need

special education and training to enable them to live semi-independently in the community in group homes or supervised apartments. Some can enter into the competitive labor market, while most will benefit from sheltered employment.

Severely retarded persons. About 3½ percent of all mentally retarded persons are severely retarded. They can learn to independently care for their day-to-day needs such as basic self-help (eating, dressing, bathing, toileting, grooming, and personal hygiene) and with special training, most individuals in this group can engage in productive work in supervised settings. While some are residents in public and private institutions, others live at home or in community-based residences.

Profoundly retarded persons. Only about 1½ percent of all mentally retarded persons are profoundly retarded. Many myths concerning an inability to learn and develop are associated with this group. Most of these people can, however, learn basic self-help with highly skilled training. Some, with adequate preparation, can be involved in work activity centers where emphasis is placed on self-help, grooming, cooperating with others, and following instructions rather than on productive work, per se. Some are institutionalized while others live with their families or in supervised group-home settings.

SOME CAUSES OF MENTAL RETARDATION

"Mental retardation is not a simple entity. It refers to a multitude of possible conditions, all of which have the common effect of significantly reducing the individual's intellectual functioning."

Dr. Philip Roos,
Executive Director, NARC

Mental retardation can be caused by any condition that hinders or interferes with development before birth, during birth, or in the early childhood years. More than 250 causes have already been identified; yet in approximately 75% of cases, no specific cause can be determined (President's Committee on Mental Retardation, 1971). The majority of causes are still unknown and are subject to intensive research. Some of the known causes are summarized here.

During pregnancy. Malnutrition, German measles, glandular disorders and many other illnesses of the mother during pregnancy can result in a child being born retarded. Lack of development of the brain before birth cannot be overcome after birth.

At birth. Extraordinarily prolonged labor, pelvic pressure, hem-

orrhages — any birth condition of unusual stress — may injure the infant's brain. Any circumstance that reduces the supply of oxygen to the brain during birth may impair the baby's mental development.

After birth. Childhood diseases like whooping cough, chicken pox, measles, meningitis, scarlet fever, encephalitis and polio can affect the brain, especially in the very young child. Glandular imbalance or malnutrition may prevent normal growth. Accidents — a blow on the head, for example — may damage brain tissue. Lack of certain chemicals in the blood which prevent the child from normally digesting his food may cause brain damage and result in mental retardation.

Data published by the President's Committee on Mental Retardation suggests that some seventy-five percent of our nation's mentally retarded citizens come from urban and rural poverty areas. Malnutrition, lead poisoning from ingestion of lead-based paint flakes peeling from tenement walls, and other health hazards associated with poverty situations can cause mental retardation. In addition, children in disadvantaged areas simply are not exposed to the most common day-to-day experiences of more fortunate youngsters. Research now suggests that such understimulation can seriously impede optimal development and cause mental retardation.

Genetic irregularities. These result from the abnormality of genes inherited from the mother and father, or from disorders of the genes caused during pregnancy by over-exposure to X-rays, infections and other causes. Genetic influences may impair the development of the brain before, during or after birth.

HISTORY OF ATTITUDES AND PRACTICES CONCERNING MENTALLY RETARDED PERSONS

> **"Connecticut's first house of correction in 1822 was for rogues, vagabonds, the idle, beggars, fortune tellers, diviners, musicians, runaways, drunkards, prostitutes, pilferers, brawlers, and the mentally retarded."**
>
> **Deutsch, 1949**

Since mental retardation was not defined in behavioral terms until the 18th century, the condition was simply treated as another form of deviancy, and reactions toward mental retardation were inconsistent. While the Spartans of ancient history condemned a defective infant to be placed unprotected on a mountain top to die, the early Christians thought that these children should be protected by the church. The mentally retarded person during

the Dark and Middle Ages was protected by some cultures, served as a court fool in others, was worshipped as a communicant with the gods in some places, and was harassed and taken advantage of in others. Renaissance royalty thought that "collecting" mentally retarded people for their court was fashionable.

Attitudes became even worse in the 17th and 18th centuries when Demonology was prevalent. Mentally retarded persons were thought to be inhabited by demons and spirits. Many were feared and persecuted while others were imprisoned or sentenced to die. In the early 1800's, retarded people, paupers, and sick or poor persons were sold to the bidder who would take responsibility for them for the lowest amount of public support money.

In general, it was believed that if deviance could not be prevented or reversed, these persons should either be segregated or destroyed. Often, the parents were blamed for the child's abnormalities.

Institutional Care

"The important thing is to integrate the retarded as much as possible into normal activities and services rather than separate them."

Richard M. Nixon, 1970

Prior to the 1800's, there was no institutional or systematic care of any kind for mentally retarded persons who were either hidden away in homes or placed in asylums with a variety of people who were then perceived to be physical and social misfits. The first institution was opened in France during the early 19th century. Pioneers in Europe in the field of institutional care for the mentally retarded were Itard, Seguin and Esquirol. The first institution in the United States was built in 1848 during a period when people had a fairly positive outlook concerning mental retardation; and by 1890, there were 20 such facilities scattered throughout 15 states. These first centers were quite different from today's institutions and were founded specifically to educate and train mentally retarded persons for return to the community. The vast optimism in the field at that time, however, led to unrealistic expectations which could not be fulfilled in many cases. Thus, within a short time, a cloud of pessimism began to overlay efforts to help the retarded, and a trend began toward moving them into isolated rural areas away from the community setting.

At the turn of the century, attempts to protect the retarded from society reversed; thus the emphasis was on protecting the public from imagined harm. Up until World War I, an alarmist period existed, partly due to an emphasis on eugenics (improving the human species by controlling hereditary factors in marriages). This concept brought intensified efforts toward sterilization and regulated marriage. More and larger institutions were built in an effort to segregate and warehouse retarded persons in, what turned out to be, a highly dehumanizing environment. Institutions were inadequately funded and understaffed, and many residents were utilized as a "captive work force".

The early 19th century was a bleak period for mentally retarded people since they were thought to be naturally disposed toward crime, prostitution and other forms of anti-social behavior. After World War I, however, scientific concepts began to replace such negative perceptions of retardation, but even though the rationale for large institutions was no longer considered valid, these facilities continued to function in the same way they had in the past. Even today, similar reasoning is followed in building and operating many residential facilities, and deplorable conditions remain without significant notice by the mainstream of society. Some facilities house 4,000 residents or more with enough staff to take care of only one-fourth of that number.

Over the years, several destructive residential service models have evolved which unfortunately continue into the present (Wolfensberger, 1969). These models have been identified on the basis of services or treatment afforded mentally retarded persons; and the following six are presented as the most commonly recognized:

1) **a sick person** — retarded people are cared for in hospital-like settings as though they are diseased, and terms like "patient" and "ward" are used. An emphasis only on the physical condition of the person is typical.

2) **a sub-human organism**—mentally retarded persons are viewed as not being completely human and are housed in indestructible settings with minimum freedom or opportunities for choice. Basic human rights do not apply.

3) **a menace** — a prison-like setting protects society from the threat of retardation, and techniques for supervision may bear overtones of persecution.

4) **a burden of charity** — mentally retarded persons are viewed as a responsibility of public charity, and it is believed that residents should be unduly grateful for minimal services, and suffer hardships without complaint.

5) **the holy innocent** — retarded people are innocent, harmless, "eternal children" even after reaching chronological adulthood.

6) **the object of pity** — the mentally retarded person is viewed with a "there but for the grace of God go I" attitude, and emphasis is placed on minimizing risk and providing "fun" programs for residents.

These models can still be found in institutions around the country today and have continued in a self-perpetuating cycle. Thus, predictions made about mentally retarded persons come true because the environment constructed for them in institutions allows no other behavior to develop except that which has been predicted.

Advances and Changing Attitudes Concerning Mental Retardation

"We can love a person only to the extent we are not threatened by him."

Carl Rogers

The continuation of dehumanizing conditions within institutions and the absence of adequate community services for mentally retarded persons resulted in several progressive developments from 1950 to the present. The National Association for Retarded Children, now known as the National Association for Retarded Citizens (NARC), was founded in 1950 by 42 parents of mentally retarded children, representing 23 local units across the country. The Association has now grown to include approximately 245,000 adult members affiliated with over 1,500 state and local member units. The youth component of NARC (Youth-NARC) was organized in 1967 and now has more than 20,000 members between the

ages of 13 and 25 working in 43 state member units. The emphasis in the Association's initial years was to provide educational and recreational services in the community for all levels and ages of mentally retarded people. Improving residential facilities, promoting the establishment of community-based services, delving into causes and the prevention of retardation, increasing public education and awareness, and other such activities are being vigorously pursued by NARC units today.

The President's Panel on Mental Retardation was appointed in 1960 by President John F. Kennedy. This group had a very positive impact in the area of governmental concern for mentally retarded persons in institutions and in the community.

In 1968, NARC, the President's Committee on Mental Retardation (PCMR), and the American Association on Mental Deficiency (AAMD) adopted residential care as a top priority. During that year, NARC issued the **Policy Statements on Residential Care,** and PCMR also published two important documents: **Changing Patterns in Residential Services for the Mentally Retarded,** and **Residential Services for the Mentally Retarded: An Action Policy Proposal.** The PCMR papers covered such topics as conditions in present-day institutions, alternative models for residential services, a recognition of the human and civil rights of the retarded, and the development of programming specifically tailored to the nature and degree of each individual's handicap.

AAMD had earlier published (1952) a special committee report on standards for institutions. These standards were an important first step toward objective evaluation of residential services. Seven years later, AAMD's Project on Technical Planning in Mental Retardation undertook a major standards development project resulting in the 1964 **Standards for State Residential Institutions for the Mentally Retarded.**

During this period, NARC and the American Psychiatric Association (APA) also showed interest in the development of residential standards in order to establish a formal accreditation program for residential facilities. AAMD, the Council for Exceptional Children, and United Cerebral Palsy Associations, joined NARC and APA in forming the original Accreditation Council for Facilities for the Mentally Retarded whose standards document (ACFMR, 1971) was adopted in May of 1971. Voluntary accreditation of state residential facilities began in 1971, and, since that time, standards have also been developed for non-residential facilities.

The effect which these movements had on the field of mental retardation was not isolated or independent, and each effort gave a boost to endeavors of other persons or organizations. More has happened in the past 20 years to improve the lot of mentally retarded persons than occurred during the total period of time that preceded these years. And the field is still open for advocates to

lend a hand. Trends today are toward deinstitutionalization of retarded persons and their integration into community life. Currently, most states are trying to develop comprehensive services at the local level for their handicapped citizens, and efforts are being made to give mentally retarded persons the necessary attention to enable them to live more productive and satisfying lives. Education of the retarded child in the community has increased markedly during the past 20 years. In 1970, there were seven times more public school systems offering special education than there were in 1950. However, this increase was sufficient to serve only some 40 percent of the children needing such aid. Parents of mentally retarded offspring as well as other groups of developmentally disabled children all over the country are demanding that these children be given the same educational opportunities afforded to their non-handicapped peers, and they are winning.

Proposed expansion of vocational training and habilitation programs, day care centers, and medical, recreational, and educational services at the local level will also increase opportunities for better service to both institutional and community residents who are mentally retarded. The building of smaller, more home-like residential settings as well as the provision of more sheltered workshops will help in securing equal rights for mentally retarded persons, and will also benefit the community as a whole, too. Even under the limited training and educational opportunities now available, an estimated 87% of retarded men are employed; that's only four percent below the rate for men in the general population. Each one dollar spent in habilitation of 18-year-old mentally retarded men generates an estimated increase in future earnings of fourteen dollars (Conley, 1973).

Today, due to more public education efforts concerning mental retardation, many people's attitudes toward the subject are being modified. The social stigma once attached to mentally retarded persons is lessening as they are perceived to be more like us than different from us. The advocate can play a vital role in helping retarded citizens gain tolerance from others and acceptance by the community.

A new role perception of retarded persons is found in the Developmental Model and the Normalization Principle mentioned in Book I which hold that the retarded person is capable of growth and learning and can be helped to develop by being provided with an atmosphere as similar as possible to that of a normal person, with some features added to compensate for handicaps. The advocate can help his protege to learn to cope with all of life's experiences, both good and bad, with more success. New experiences, new people, new skills, and new choices will encourage the development of the protege to his fullest potential, whether he is in an institution, in the community, or making the transition between the two.

ADVOCACY ROLES AND NEEDS OF RETARDED PERSONS

"Give me a fish, and I eat for a day; teach me to fish, and I eat for a lifetime."

Anonymous

Before we go on to talk about actual examples of Citizen Advocacy for various groups of retarded persons, perhaps we should restate the definition of the concept as given in Book I of this series.

Citizen Advocacy for mentally retarded persons is basically a one-to-one relationship between a capable volunteer ("advocate") and a mentally retarded person ("protege") in which the advocate defends the rights and interests of the protege and provides practical or emotional reinforcement (or a combination of both) for him. All of this occurs within the framework of a structured advocacy system.

The illustrations given in this section of the book depict the variety and flexibility for actual advocate-protege relationships within the boundaries of this definition. They show how an advocate can provide either friendship (emotional reinforcement) or practical guidance (help with the basics of daily living) or a combination of the two for a protege as well as acting as a spokesman for his rights and interests.

Advocacy for Institutionalized Residents

"Abandon Hope, all ye who enter here."

Dante

As pointed out in Book I, the need for advocates for residents in institutions is particularly great because of the de-humanizing conditions that exist in many of these facilities. Institutions are typically large, over-crowded, under-financed and understaffed, all of which result in a sterile, regimented atmosphere with little programming or personal attention for residents. Fortunately, many residents maintain some contact with the outside community through the parents. A large number, however, are confined to the institutional environment without this needed social contact or representation by a person outside the system.

What can an advocate do to help institutionalized residents? Besides providing much-needed individualized attention to relieve the loneliness and monotony of institutional life, the advocate can open doors to the future for his protege, and he can act as that resident's spokesman if he sees that the institutional

system is not acting in his best interests. The following are examples of advocacy for institutionalized residents.

KEITH AND AN ADVOCATE FAMILY

Although Keith is a resident of an institution at night during the week, he now spends most of his days and many weekends working in various homes as a gardener and handyman. Sometimes he works at a car wash. The first time Keith was ever outside of an institution without an attendant was when his new advocate, Mrs. Carter, came to take the young man to her home to work in the yard. Devoting much patience and many hours to teaching Keith, Mrs. Carter showed him the difference between weeds and flowers and about gardening tools. The "deal" between them was that he was to call her if he was not sure whether the plant was a real weed or a small flower. Now he has worked up to doing some of the planting himself.

Keith's expertise, cultivated by the Carter family, also extends to cooking, painting walls, handling a saw, riding a bicycle they bought for him to make it easier to go from job to job, swimming, rowing a boat, catching and cleaning fish, and choosing his own new clothes.

Besides all of these "firsts", the Carter family helped Keith to celebrate the first holiday he ever remembered spending outside of an institution. The satisfaction that both the advocate family and their protege feel about the skills Keith has acquired during their relationship has enriched all of their lives, and they are looking forward to the day when he can leave the institution and move into a group home or apartment to fully enjoy his new found independence.

JOHNNY AND HIS NEW FAMILY

When a 45-year-old mother and her teenaged daughter entered the advocacy program, they never dreamed that it would lead to the addition of a new family member. Their protege, ten-year-old Johnny, was one of six children who were abandoned at an early age. The other five children were placed in foster homes, but because he was "slow", Johnny was institutionalized.

When the family first met Johnny, he would hide his face, hang his head, and stiffen noticeably. On their initial outings, the daughter couldn't interest him in going to a carnival or a show because he was afraid he would "miss out on being in a real home". He had never kissed anyone, and whenever he saw a picture of a mother and child, he would turn it over and look away.

Gradually, through being his advocates, the family came to love the little boy and wanted to take him home with them for good. During his stay in the institution, he had never shown much interest in learning, but all this changed after he had been in his new home for only five weeks. In one week, he learned to use a telephone, a toaster and a can opener. It took a little longer for him to learn that it was possible for him to displease the family without being sent back to the institution, and that he didn't have to hide his new toys so they wouldn't be taken away or broken by other children.

At the grocery store, Johnny learned to push the grocery cart, what flour is and what you can make with it, and later, how to bake cookies and "make the raisins stay where they are supposed to". And the family learned that Johnny was troubled because he didn't know if he had a middle name or not, and he wanted one.

The adjustment for all of them wasn't perfectly smooth. Johnny was possessive of his new mother; and when she bathed or changed clothes, he always waited for her outside the bathroom door. He was jealous when she paid attention to anyone else. And there were learning problems at school. Verbally, he was

able to keep up with his special education class; but he couldn't read, printed poorly, had limited arithmetic skills, and his attention span was extremely short. However, with patience and the help of his teachers, his reading and writing slowly improved. He was greatly helped when it was discovered that he had visual perception problems (seeing double) which had gone unnoticed, and he was fitted with glasses.

The commitment to take a retarded child from an institution into the home is a big step, and only a small percentage of Citizen Advocacy relationships will probably result in foster or adoptive parenthood situations, but Johnny and his new family are glad theirs did.

Advocates and the Community Adjustment Process

"Today I wear these chains
And am here —
Tomorrow I am fetterless,
But where?"

Edgar Allan Poe

Current estimates indicate that less than three percent of the retarded persons in the United States reside in public institutions. Thus, fortunately, the great majority are able to remain in the community. Retarded persons leaving the institutional setting to live in the community are greatly in need of help in order to make the transition successfully. In many cases, retarded persons leaving the institution are entering an unfamiliar and frightening world, and many will be unprepared to cope with probable periods of loneliness, anxiety, and frustration. If someone is not available to help these people through difficult times, the result can be, and often is, returning them to the institution. If they fail in their first chance at independence, through no fault of their own, imagine how difficult making good at a second chance will be for them, if one is ever offered. Just a little help from an advocate could make the difference between a successful adjustment or a failure. The following are examples of how an advocate can assist his formerly institutionalized protege live in the community.

BILL AND DAVE

When Dave decided to enter his local Citizen Advocacy program, he knew that due to the two jobs he was holding down, he would be unable to spend a great deal of time in an Advocate-Companion type of relationship; but nevertheless, he wanted to help. The local coordinator in Dave's town matched him with a

protege named Bill, a young man who had just left an institution and was now sharing an apartment with two friends.

After having talked with Bill initially, the coordinator felt slightly suspicious concerning Bill's new job as a dishwasher in a local restaurant. It seemed to her that Bill's wages were not adequate for the amount of time he was working. Rather than delving into the situation herself, she matched Dave with Bill and put him on the trail, and she monitored the relationship as it progressed. After a few contacts with Bill, Dave learned that he was working between 65 and 70 hours a week for $50. The employer was not keeping records of overtime and Bill was being cheated. He suspected that something was wrong, but he didn't know what to do about it and had never had the opportunity to discuss it with anybody before he had an advocate. Dave went to the advocacy office's local Advisory Committee and located a lawyer, and together they initiated an investigation by the Federal Wage and Hour Bureau on behalf of the protege. The final outcome was an improvement in both wages and record-keeping for Bill. Shortly thereafter, Dave was able to give up one of his jobs because of a promotion in the other; and with more free time, he and Bill were able to spend more hours together, expanding what had been mostly a practical relationship into a friendship as well.

ELLEN AND DIANE

Ellen is 19 years old and had lived most of her life in a public residential facility for mentally retarded persons. Recently she moved into a half-way house for mildly and moderately retarded young women and is working hard in a nearby textile factory. Her advocate, 20-year-old Diane, read about the local Citizen Advocacy program in the newspaper and volunteered her services. After the screening and training periods, she was matched with Ellen. The two young women get together about once a week to go to a movie, or a fashion show, or just to go shopping. In addition to coaching Ellen in connection with a special reading and writing program held at the half-way house, Diane has also taught her how to shop wisely and get good values for her money, and how to coordinate clothes and apply make-up tastefully. Also on the practical side, Diane sometimes takes her protege to the factory to work. Both of them enjoy gardening, and they received permission to spade up a small plot of ground in back of the half-way house where they have planted tomatoes, okra, onions, and other vegetables.

In the near future, Diane is planning to be married, and Ellen has become quite involved with the wedding preparations, choosing the bridal gown, selecting the invitations, etc. This situation gives Diane an opportunity to discuss the meaning of marriage with Ellen and to prepare her for possibilities in her own future.

Advocacy and Proteges Who Have Always Lived at Home

"There was a child went forth every day
And the first object he look'd upon,
That object he became,
And that object became part of him
For the day or a certain part of the day,
Or for many years or stretching cycles of years . . ."

Walt Whitman

The needs of proteges who have always lived at home may be very much the same as those of ex-residents of institutions who move into the community. Even though these proteges have homes and possibly go to special schools in their cities, they may still be isolated from the mainstream of society with no true close personal relationships. And even though they may have parents who care about them, these parents may not know how to go about obtaining the needed services and education to which their child is rightfully entitled. Advocates can perform valuable services in these areas by acting as friends and spokesmen for the proteges and their families.

PAUL AND MRS. IRENE REYNOLDS

Paul is a six-year-old boy from a black family. He has five brothers and sisters, and his mother works long hours to support her family. Paul's father died when the child was very young. During the early years of his life (since all of her other children are non-retarded) Paul's mother thought that he was simply a behavior problem. He sometimes threw tantrums and pulled out patches of his hair, but usually he was sullen and very withdrawn. Little progress had been made in the areas of toileting, dressing, and self-feeding. It wasn't until recently when he got big enough to go to school that he was diagnosed as mentally retarded. His mother didn't know where to turn for help. The local advocacy office received word of Paul through a referral by a local agency and assigned him a black advocate, Mrs. Irene Reynolds. She is a school teacher with a family of her own, but she finds time to visit the protege's family each week and is working on obtaining the needed services for Paul. At first, he would have nothing to do with her, but gradually, as she brought him colorful books from the library and took him for walks in the park, he became more open and responsive, and now looks forward to "Mrs. Irene's" visits. She worked with the mother as well, giving her ideas about the best way to handle her son so that he can receive all the indi-

vidual attention possible in his large family. Mrs. Reynolds and Paul's mother still have a long way to go in helping him to develop as much as his potential allows, but at least they have made a start.

SUSAN AND TRICIA

Susan and Tricia live right down the street from each other, but it took the local Citizen Advocacy office to bring them together. Susan, 16, is mildly retarded, and has also been blind since birth. She remembers sitting at her bedroom window and hearing Tricia calling out to friends as they drove by coming home from school and wishing that she could get to know her lively neighbor . . . Susan is an only child, and that fact combined with her handicaps has made her very lonely.

Tricia is a year younger than Susan and leads an active life as a member of her school's pep squad as well as singing in the choir and baby-sitting frequently. She also has a boy-friend named Terry who takes up plenty of her time, but when she heard about the advocacy program through publicity by her local chapter of Youth-NARC, she decided to join.

Now, the two girls get together several times a week to listen to records, go out for a Coke, or just talk. And since their relationship began, Susan has started keeping a journal with the help of her mother, and most of it is full of her activities with Tricia and the new friends she has made. A recent entry read: "Today was the big bonfire at Tricia's school, the one before the homecoming game. Tricia and her boyfriend Terry drove me over to the field where the bonfire was held, and I got to smell the wood burning and hear the kids yelling and everything. It was really something."

Tricia thinks Susan is "really something", too; and although the young advocate is only 15, she has become one of the most enthusiastic and active members of the program in town. Because of her outgoing personality and talent for expressing herself, Tricia is often called upon by the local coordinator to speak to service clubs and youth groups, and she has been responsible for bringing many new advocates into the program.

YOUR INVOLVEMENT AS AN ADVOCATE — Emotional, Legal and Financial Considerations

"Am I my brother's keeper?"

Genesis 4:9

Whether your protege resides in an institution or in the community, your role as an advocate will take on dimensions which you may not have experienced in any other volunteer situation.

When some people first hear the word "advocate," they shy away from it, uncertain of its meaning. Many think that is has strictly legal implications because they often hear lawyers referred to as advocates. Advocacy should not be looked upon as "frightening", but it does involve a deeper commitment than is usually found in the traditional volunteer program. An advocate is volunteering to serve a specific person, not to serve the impersonal institution the protege lives in or the agencies that handle his case. Compared to a "traditional volunteer", an advocate is more independent, more involved and probably more serious about this role than he has been about previous human service commitments. He is half of a one-to-one relationship which is special to both parties, whether the needs are primarily emotional or practical.

A good example for making comparisons between the advocacy role and that of other volunteers is the person who volunteers to spend a few hours a week working at a local institution. This volunteer will first be indoctrinated to the institution's rules before he is assigned, and he will frequently receive a list of "DON'Ts" which is highly detailed and specific in its admonitions ("DON'T visit the institution during any hours other than those specifically designated as volunteer hours", "DON'T forget to sign in and out . . ."). It's true that advocates go through a screening and orientation process, too, but it's less rigid and more designed to provide tools of knowledge for the advocate to utilize ingeniously rather than to teach him by rote "how to be an advocate". Many volunteers to institutions are put to work giving indirect services like mending, filing, or typing, and only participate in group-oriented recreational activities with residents. They are highly supervised in their duties, and will probably only be on the fringes of programming with no opportunities to give their evaluations of the system.

On the other hand, the advocate has the opportunity to speak out and initiate changes in his protege's behalf which even the parents may not be able to do because of fear or reprisal in the form of decreased services for their child. This does not mean that the advocate is free to come to hasty conclusions or "make waves" in relation to the institutional setting before he has had the opportunity to study and comprehend the system, however. This is part of the responsibility involved in being an advocate; patience, wisdom and good judgment are necessary in handling injustices to the protege. And it is the responsibility of the local coordinator to monitor the relationship and make sure the advocate knows that he can call on the local office for advice at any time if he is in doubt about the best way to handle any given situation.

The advocate must be willing to risk emotional involvement with another person through disappointments as well as good times. He must be ready to act in his protege's behalf when the

mentally retarded person's rights are being jeopardized even if it brings criticism to the advocate. He must be willing to be on call for his protege at the risk of inconvenience to himself (an emergency call at midnight, for example). The advocate must be ready for the possible involvement of other members of his family with the protege's welfare, and his family should be ready to accept the advocate-protege relationship.

Some prospective advocates worry about legal liabilities. The advocate involved in an informal relationship (not a guardian, trustee, etc.) is legally responsible for his protege to the same extent that a Little League baseball coach or a Boy Scout leader are liable for their charges during the time they are supervisinng them. Essentially, this simply means that he should exercise logical, reasonable caution during the time the protege has been turned over to him. The advocate is involved legally to the same degree that any person is responsible for injury to another person who is in his home or automobile. Safety of the protege should be of top priority at all times, and the best way for the advocate to protect himself is to maintain sensible insurance coverage and keep his property and automobile in good order. The advocate should remember that legal counsel is always available through the local advocacy office and the legal component of its Advisory Committee.

The advocate is only responsible financially in the relationship for paying his own portion of the expenses incurred in any activity. He should talk with the protege and his parents about finances, and the protege should pay his own way whenever possible. Situations will, of course, arise where the advocate may want to take the protege out to dinner on a special occasion, for example, or the protege may want to "treat" the advocate. Each relationship will differ somewhat in these matters and you will have to use your own judgment. In the case of any financial problems, unusual expenses, or emergency situations which might arise, the advocate may want to call on the local office's Emergency and Reimbursement Fund (if such a fund has been budgeted, as discussed in Book II). Remember that there are many activities you and your protege can enjoy at little expense. (See page 31.)

GOING THROUGH CHANNELS AND CUTTING RED TAPE TO ENSURE YOUR PROTEGE'S RIGHTS

"Those who deny freedom to others deserve it not for themselves, and under a just God, will not long retain it."

Abraham Lincoln

As an advocate, you may find that you want to get involved not only in a friendship with your protege, but in the fight to ensure

his rights as well. In order for an advocate to fill this role as a protector of rights and an obtainer of services for his protege, he must be knowledgeable of the proper channels open to him for gaining and safeguarding these prerogatives.

Mentally retarded persons have the same Constitutional rights as all other citizens. Your rights and those of retarded persons cannot be abridged or denied unless legally prescribed methods are employed and consideration is given to specific areas. An inability to exercise a specific right is not evidence that the mentally retarded person is unable to exercise his rights in general. When a person is determined to be incapable of handling one or more of his rights independently, someone should be appointed to ensure that a re-evaluation of that person's ability to employ his rights occurs periodically, and that the abridgment or denial of rights is not unreasonable or arbitrary.

It is frequently stated on a philosophical level that retarded persons are entitled to the same rights as others, but, in practice, there is an obvious discrepancy. This inequity stems in part from our cultural heritage to react negatively to all forms of deviancy, and because of the traditional and prevalent image of the retarded person as an "eternal child" who, regardless of chronological age, always requires paternalistic protection.

The rights of retarded persons residing in institutions and the community have been the object of considerable abuse, and efforts have, thus, become international in scope to remedy neglect in this area. In 1968, the International League of Societies for the Mentally Handicapped (ILSMH) adopted "The Declaration of General and Special Rights of the Mentally Retarded". The full text of the declaration is presented in Appendix I.

Also in 1968, NARC issued its "Policy Statements on Residential Care", dealing with rights of institutionalized mentally retarded persons. In addition, a National Conference on Human Rights for the Mentally Retarded was held in Texas in 1971. This conference was organized to specify courses of action for achieving rights for the mentally retarded in legal, social, educational, employment, and general areas (Diana, Pool, 1971). Some of the rights in these categories which were considered were as follows:

Legal

- **"Life, liberty and the pursuit of happiness"**
- **Rights as guaranteed by state laws and constitutions**
- **Right to legal counsel, especially when commitment to an institution is under consideration**
- **Right to vote**
- **Right to a continuing dynamic review of his human and legal rights**
- **Right to use of the court system**
- **Right to make contracts, draw up a will, obtain licenses, establish a good credit rating**

Social

- **Right to personal dignity**
- **Right to contribute insofar as possible — pay taxes, give opinions, do things for others**
- **Right to community living**
- **Right to social acceptance**
- **Right to normalized family living**
- **Right to satisfying living arrangements, in or out of the family unit**
- **Right to be treated in a manner consistent with his chronological age**
- **Right to marry**
- **Right to reproduce**
- **Right to home-and-family jobs or responsibilities**
- **Right to make decisions, which includes the right to make mistakes**
- **Right to treatment approaches which are suitable for his needs**
- **Right to reject opportunities offered him**

Educational

- **Right to education, *broadly* defined**
- **Right to choose his own educational goals**
- **Right to be in "normalized" school and have contact with non-retarded individuals of his own age**
- **Right to have teachers who hold the child's basic human rights foremost**
- **Right to be accepted at his learning level**
- **Right to be taught to think for himself**

Employment

- **Right to be trained for available jobs**
- **Right to have his job described by a non-stigmatizing title rather than as a "low-level job"**
- **Right to change jobs or job training as workers in general do**
- **Right to seek, gain, and hold employment to the best of his capabilities**

General

- **Right to be judged by the same social and legal standards as people in general**

Advocates may find that mentally retarded persons in institutions have difficulties in retaining their rights, and special knowledge is necessary to help remedy such situations as over-use of drugs and physical restraints, dehumanization of residents, or loss of their legal rights such as voting or owning property (see Book I, pg. 13.)

As a Citizen Advocate, you will find that sources today for gain-

ing knowledge and back-up in your fight for your protege's rights are constantly increasing. Besides your local or state advocacy office, you can also directly contact such groups as the National Center for Law and the Handicapped in South Bend, Indiana, which is jointly sponsored by NARC, Notre Dame University, the Council for the Retarded of St. Joseph County (Indiana), and the Family Law Section of the American Bar Association. Other helpful resources include NARC's National Legal Advocacy Committee, and the American Bar Association's Committee on Law and the Mentally Retarded.

What Can You Do?

What can you as an advocate do to ensure that your protege is benefiting from the human and Constitutional rights to which he is entitled?

- Be knowledgeable of your own rights and those of your protege.
- Make careful observations of problem situations that deny or abridge these rights and try to get a perspective on all sides of the issue, while carefully documenting all aspects of problems as thoroughly as possible.
- Bring such information to the attention of the Local Citizen Advocacy office. The coordinator may help you evaluate the problem or he may call in a member of the Advisory Committee who has the needed expertise in that particular area.
- If the issue can be solved by your simply contacting one person—an unfair employer of your protege, for example—go this route first. If this fails, then look higher up.
- When taking further steps to resolve a problem on your own, alert the local advocacy office of your intentions so that help will be available if needed quickly.
- **Then,** determine the key offices, agencies, boards, and persons in positions of power in your area of concern, and approach them with **an action plan to remedy the problem.** Use any contacts you or your friends may have who can get you in to see these people.
- Don't just complain about the problem—be informed, have ideas of your own, plan ahead, and in planning, try to see the situation from the viewpoint of these officials and consider their busy schedules since the most influential persons are usually involved in several different, important areas simultaneously. This may work to your advantage since they can advocate your cause on several fronts. Be enthusiastic and try to spread that enthusiasm to them and get them to identify

on a personal basis with your protege and his problem. Express your gratitude for any help they can give you, and especially if they hold an elective office, let it be known to the public through publicity efforts that they are championing your cause. (Be sure and get their titles and the spelling of their names right!) Don't, however, speak for the official without his permission. Furnish reporters with the official's own remarks, not your paraphrases. By giving helpful public figures good visibility through the media or at public meetings, you will ensure their continued cooperation in the future.

- One good strategy to help you get organized in advocating for your protege in the community is to keep a notebook of names, addresses, and phone numbers of people who are not on the advocacy office's Advisory Commitee, but who are in the position to help your protege or the advocacy program. You may want to share this list with the local coordinator who can then add it to a master file of community resources. Included could be: lawyers; employers; physicians; media personnel; religious leaders; officers of the Chamber of Commerce; members of professional organizations and service clubs; city, county, state and federal government officials; people who work for the retarded in any area like special education, vocational rehabilitation; college or university professors of subjects like psychology, psychiatry, sociology, or teacher training.
- During the process of negotiation, call on the local Citizen Advocacy office and Advisory Committee for advice or help if necessary.
- If the action taken is accepted favorably, be sure that all persons involved follow through to ensure that the protege's situation is indeed improved, and not just discussed and then dropped.
- If the action is not successful, contact the local coordinator again and fill him in on the situation and on the fact that the "customary" approach to remedy it has failed. Then, you can resort to alternate plans of action. (Examples: intensification of publicity efforts via the media to gain support from the general public, or taking legal avenues available to private citizens through the courts. The legal component of the Advisory Committee could help you here.)

PHASES IN ADVOCATE-PROTEGE RELATIONSHIPS

"A friend is a gift you give yourself."

Robert Louis Stevenson

The Beginning

As a new advocate, you may naturally have some tense feelings in regard to your initial contacts with your mentally retarded protege, and you will want everything to go as well as possible. By this time, you should have attended several orientation sessions at your local advocacy office where the coordinator will have covered the information contained in this book plus other factors applicable to your local program and your specific protege's case history. These sessions should have given you some idea of what to expect in your relationship with the protege, what he and his family will expect from you, and how you can best serve his needs, thus reducing any anxiety you may have felt over dealing with a retarded child by replacing negative feelings with positive knowledge.

Initial Contact

In your initial contact with your protege, you should plan a brief, informal encounter, with parents of the protege and/or the local coordinator or an experienced advocate present. Be sure that you know specifics about your protege (any nickname he may have or any activities he particularly enjoys) so that you can lay the groundwork for future get-togethers. Give the protege and his family some facts about yourself and tell them how you can be reached by giving them home and business phone numbers, etc. No formality is necessary, and the protege may not even know you as "his advocate," but just as a **friend.** It is best to keep the activities in these first meetings fairly simple and as spontaneous as possible until you and your protege have gotten used to each other. For example, going for a walk or out for an ice cream cone is preferable to more complex activities like a fishing expedition or a shopping trip.

Here is a list of suggested activities that are inexpensive and so simple you may overlook them, forgetting that they may be totally new to your protege. Activities should, of course, be based on the protege's age, interests and capabilities:

- Ride bicycles.
- Take a boat ride.
- Visit a farm.
- Play marbles or other basic games.
- Take photographs.
- Go to a concert, pop or classical.

- Windowshop.
- Go to the drag races.
- Bake a cake.
- Go to the beach and make a sandcastle.
- Watch TV.
- Go to the movies.
- Do your laundry.
- Defrost the refrigerator.
- Take your car through the car wash.
- Introduce the protege to a typewriter.
- Go to the beauty shop.
- Play a musical instrument.
- Go to the library.
- Visit the zoo.
- Plant a garden.
- Fly a kite.
- Go to a carnival or fair.
- Visit a pawn shop.
- Go to church.

Remember, it's mutually sharing an experience that's most significant, not the activity itself.

It is extremely important to be consistent in your contacts with

the protege. Set aside definite blocks of time to spend with him, and do not initiate the relationship at a higher level than you will be able to maintain later; for example, if you anticipate being able to see your protege once every two weeks, don't lead him to expect more by seeing him several times a week initially and then letting him down later. There is frequently a tendency for a new advocate to begin a relationship with great enthusiasm, high hopes and probably unreasonable objectives which he wants to help his protege attain. When the newness wears off, and the protege has not fulfilled all of the advocate's expectations, the advocate may become depressed and even want to drop out of the program. If he is encouraged to continue the relationship and to modify his ambitions for his protege somewhat so that the protege won't feel that he is always disappointing the advocate, the relationship can begin to grow in the right direction. Each of the two will begin to really accept the other for the person he REALLY is, and they can have a more satisfying friendship. The advocate should not measure his own success in his role solely on the response of the protege, and he should not be discouraged if his protege does not seem to respond as well as other proteges he has contact with. Each *retarded* person is an individual with his own potentials and difficulties. You should measure your success as an advocate by how well you are meeting your protege's needs and representing his rights, and by the progress he makes at his own pace in **his** own way. It's natural for your ego to want some positive feedback from your protege, but some retarded people may not be able to provide this reinforcement, and you must accept him as he is.

Other important points to remember in this initial phase of the relationship include:

- **Spend time alone and with your protege prior to your meetings in order to plan activities that will be meaningful to him, and determine them according to his needs and desires. Don't wait until the last minute to plan what you two will be doing. Don't substitute gifts of material things for time spent in activities and on personalized attention.**
- **Remember that your first allegiance is to your protege, not to the program or institution or service agency.**
- **View your protege as a friend and introduce him as such to others. (It may seem awkward to introduce him as your "protege.")**
- **Do not overprotect your protege. If he is to experience as normal an environment as possible, he should be allowed to take normal risks: like physical risks in sports, or emotional risks (having a pet which could run away or become ill and die). Such experiences are a part of the daily lives of normal children and should happen to retarded children as well.**
- **Don't be afraid to express anger with your protege if he tries to test you by annoying you. Don't coddle him or let him take advantage of you. Learn to say "no!" He will benefit.**

- **Don't encourage dependency on you by your protege. Your goal should be to help him become as independent as possible.**
- **Do not underestimate your protege's abilities. Offer him a challenge sometimes. Do not constantly expect more of him than he is able to deliver, but let him surprise you sometimes with what he really CAN do.**
- **Try to listen as much as you talk to your protege, if at all possible in your particular relationship.**
- **Choose some activities where you are on an equal or even subordinate basis with your protege, and he can teach you something.**
- **Be patient, and remember that your protege is a** person **first, and a** mentally retarded person **second.**

It is very important that the advocate maintain close contact with the local office and coordinator during the initial phase of the relationship. During the first six months, the advocate should maintain weekly communication with the local office, whether it is in person, by phone, or by a written activity report of significant experiences or activities which were participated in by the pair. Your local office should offer group meetings for new and experienced advocates from time to time so that you can share your triumphs, joys, problems and frustrations with others who are having or have had similar experiences. The advocate should always feel free to call on the local coordinator, other staff members, or members of the program's Advisory Commitee for counsel. He should rely on his own judgment in making decisions concerning the progress of the relationship, but he must keep the local office informed so that they can assist him, determine strengths and weaknesses of the relationship, and evaluate the program as a whole.

The advocate should also get to know the parents, teachers, and professionals who are involved with the protege so that all can work together to benefit the child. Avoid secretiveness and competition in regard to the parents of the protege, and respect their wishes relating to the activities you plan for the child. The last thing an advocate wants to do is cause strife in the home of the protege.

The Stabilization Phase

During the stabilization phase or main portion of the relationship (after the first six months have passed) the advocate will be more on his own. He should still maintain contact with the local office at least once a month, attend group meetings when possible, and remember that he can always call on the coordinator or Advisory Committee for help in any situations which may arise. However, the advocate will have gone though a training process and developed a comprehensive picture of his protege as a person

by this time, and he should be able to handle their relationship successfully.

During this intermediate phase, the advocate may want to concentrate on specific growth and enrichment programs for the protege aimed at increasing his independence. The advocate-protege relationship should not be totally goal-oriented because this may place pressures on the retarded person to fulfill the advocate's possibly unrealistic expectations. However, the advocate may want to work with his protege on basic skill areas or toward a desired end, such as moving from an institution into the community. Many retarded persons need help in learning to take care of their personal appearance (hygiene and grooming skills). They may also need assistance in learning correct manners, social skills, self-reliance, health facts, and adaptability in adjusting to new environments and situations. The advocate may want to help his protege in learning a trade or gaining placement in a vocational program, or he may simply want to show the protege how to make the best use of leisure time. Whatever the aim, the advocate is in the best possible position to help the retarded person be all that he can be, thus developing a good self-image for the protege.

During this middle phase, regardless of its length, the advocate and protege may have to face certain crisis points together. These can range in seriousness from hurt feelings when a small child taunts a mentally retarded child and calls him names, to experiences of loss of a member of the protege's family through death or divorce. Although these are painful experiences for the protege, the advocate can cause some good to come out of them if he can show the protege how such things are a part of daily living and how the protege can gain from them.

Perhaps the crisis point may occur on the part of the advocate. For example, he could become disillusioned with his protege, or feel that he has not done an adequate job in filling his advocacy role. No matter what the critical happening may be, the advocate must learn to recognize such crisis points and realize that they are to be expected in any relationship. With the help of the local advocacy office, if necessary, both advocate and protege should be able to work through the difficulty and emerge with a more solid relationship because of it.

Termination of the Advocate-Protege Relationship

Human nature being what it is, it's natural to expect that not all advocate-protege relationships will work out beneficially for both parties. And since we live in such a mobile society, it's also logical to assume that some relationships will be split up by the necessity for one party or the other to move to another city. For these reasons, and even though we want all these relationships to last as

long as possible, we must consider the best way to handle termination of the relationships. Below are some examples of situations requiring termination.

- Valerie was a four-year-old retarded cerebral-palsied protege with a teenaged advocate named Jean. Jean wanted badly to serve as an advocate to the little girl, but Val was unable to adjust to the situation, and she cried through each of Jean's visits. The relationship was terminated; Jean was matched with another, older protege; and Val's folder was put back into the files as a possible protege for another advocate at a later date.

- Stephanie Adams, a young married woman, was matched as an advocate to Angela, a retarded woman in her early twenties who still lived at home with her parents. Although Stephanie tried hard, she simply could not get along with Angela's parents who were overdemanding and suspicious of any attempts Stephanie made to help Angela become more independent. They accused Stephanie of trying to turn their daughter against them. Angela further complicated matters by asking Stephanie for money to buy things she felt she needed that her parents would not purchase for her. The relationship was terminated, and Angela was eventually matched with an older female advocate who was in a better position to cope with the situation. Stephanie is awaiting a new protege.

- Bobbie, a young female college student, was matched with Roberta, a resident of an institution near the college. After the initial newness of being an advocate wore off, Bobbie lost interest and didn't follow through. When the advocacy coordinator tried to motivate her to continue with Roberta, who was looking forward to the visits, Bobbie complained that she was "uncomfortable" around Roberta because the protege didn't seem to respond as much as the advocate had hoped she would. The relationship was terminated; Roberta was matched with another more mature advocate, and Bobbie dropped out of the program.

- Paul Bartlett, a middle-aged man with a family, had a very good advocacy relationship with Arnold until Paul had to move to another city for business reasons. He and Arnold still correspond; Arnold has a new advocate who is much like Paul; and Paul has become involved in starting an advocacy program in his new hometown.

Even when a relationship must be terminated for whatever reason, it is possible to turn the experience into a profitable one if it is handled correctly.

In the case where the advocate must step out of the picture, certain steps are necessary:

1) **As soon as possible, an announcement should be made to the protege and his family that the advocate will be leaving, and reasons why should be explained as fully as possible.**

2) **The departure should be mentioned frequently up to the point of the actual separation so that the protege can get used to the idea.**

3) **The pair may want to plan a farewell celebration where past good times, mementoes, and promises to write to each other can be shared.**

4) **The protege should be made to understand that the loss of a friend, through no fault of his own, is a natural part of life which he should learn to accept.**

5) **The advocate should understand that over-protecting his protege is wrong, and that he must be allowed to experience loss just as the rest of us do. And, the advocate should not be allowed to feel guilty for "letting the protege down" when he has done his best to fill his advocacy role well.**

6) **If a new advocate is to be introduced into the protege's life to take the place of the friend who is leaving, the departing advocate should do everything to make the transition as smooth as possible. He may want to recommend his own replacement and introduce him into the program to be screened and trained, and he may be able to give the new advocate valuable information about the protege. Perhaps all three, as well as the parents and the coordinator, should get together prior to the first advocate's departure to introduce the new advocate to the protege as a "second friend."**

The successful termination of a relationship can make the difference between having the protege feel that one more person has let him down, or causing him to feel that his number of friends is increasing. It can also make the difference between losing the protege from the program, or keeping him in it. In the case where an advocate or protege is moving to a new city where an advocacy office is already in existence, the local coordinator of the hometown will want to make sure that the program in the new home city is aware of the transfer so that the advocate or protege can continue participating in the advocacy effort. The former advocate, moving to a community where no local advocacy office exists yet, may want to initiate a program there himself, causing ever-widening circles of advocacy offices to be created.

A FEW WORDS ON PROTEGES WITH SPECIAL PROBLEMS

Since statistics show that a large number of mentally retarded children also have associated physical disabilities, you may choose to be matched with a protege who is also handicapped by cerebral palsy, epilepsy, diabetes, or impairments in sight, hearing, mobility, or other such conditions. Sometimes these impairments are great enough that the retarded child does not measure up to our traditional picture of physical attractiveness. However, it should be remembered that these are **human problems,** not sub-human conditions. As long as the prospective advocate is aware of and informed about his protege's particular difficulties, he should be able to feel comfortable in the relationship. Application forms to be

filled out by the advocate at the local office will include a space for the volunteer to indicate whether or not he is willing to serve as an advocate to a multi-handicapped child; and all forms filled out by the protege's family should give detailed information on the protege's impairments.

Important points to remember if your protege has any additional disabilities include:

1) Be fully aware of the problem; talk with the protege's family and physician to gain a comprehensive picture of the condition, its manifestations, and medications needed.

2) If your protege must take medications at a certain time during the hours he is with you, or if he has diet limitations or other special needs, be sure to fulfill all the necessary conditions. However, never administer medicines without the full knowledge and permission of the protege's parents.

3) In case of accident or illness of the protege, follow these basic steps:

   a) Keep calm. If you must leave the protege to find a telephone, be sure someone stays with him at all times.

   b) If the accident is serious, do not move him unless he is in danger of further serious injury.

   c) Be sure you have all the necessary phone numbers or other information before taking your protege out with you; and in case of emergency, contact the parents, family physician, local advocacy office, and any other designated persons as soon as possible.

   d) Make a record of the incident available to the advocacy office in order to clarify the situation, and to protect yourself, and the program.

Since some mentally retarded people do suffer from epilepsy, and since seizures could frighten the unprepared advocate, the following information from the booklet "Your Foster Child" (St. Louis State School and Hospital, 1971) is included here:

> **"Epilepsy is a physical disorder caused by malfunctioning brain cells which cause seizures. The characteristics of the seizures vary according to type. The most common types are:**
>
> **Grand Mal: These are the most obvious seizures; the individual loses control of his body's functions and may wet or soil himself. He loses consciousness followed by the tightening of all muscles and twitching of his limbs. Other effects may be: biting of the tongue or cheek, eyes rolling up, frothing at the mouth, and the face turning blue or pale. These seizures typically last a few minutes; afterwards the child is usually sleepy and confused, remembering nothing of the seizures.**
>
> **Petit Mal: (Pronounced petty mal) This type of seizure occurs**

more frequently but lasts for only a few seconds. It consists of a brief, sudden loss of contact and is distinguished by a fixed staring look. After the seizure the person will continue his activity or conversation as if uninterrupted.

Jacksonian or Focal Motor: These seizures consist of sudden jerking movements of one area of the body and can gradually spread to involve more and more muscles.

Psychomotor Seizures: These seizures can be quite difficult to detect and are often confused with behavior problems. They consist of a switch in activity to behavior that is not appropriate to the situation. Whatever the person does will seem irrelevant. The attack usually lasts only a few minutes and there is no memory of the seizures.

Many people have warnings (called auras) that a seizure is about to occur. These are something that, at the time, is hard to detect like a mild restlessness, unusual tastes or odors, or irritability or depression. Some auras are obvious, however, like sudden dizziness, nausea, visual distortion of objects or an abrupt feeling of discomfort. If you perceive the warning signs, particularly of a grand mal seizure, move the child to a place where he will not be physically harmed when falling during the convulsion.

During the attack, you should loosen all tight clothing and wipe away saliva from the mouth. During the seizure, a person should not be held or restrained in any way; this would only create a more violent reaction. After the attack, the person may be moved to a quiet place to rest since seizures are usually followed by drowsiness. Only if a person experiences a series of convulsions in rapid succession or if the seizure seems to continue for an extended period of time is medical attention required.

The seven most common situations that bring on seizures are: 1) irregular use of medication; 2) illness of any type, especially those associated with fever; 3) emotional stress; 4) restricted activity and idleness; 5) fatigue and lack of sleep; 6) menstrual periods; 7) constipation."

Some proteges, like some non-retarded persons, have problems that are considered behavioral rather than physical—poor memory, short attention span, hyperactivity, extreme passivity, poor impulse control, or tendencies toward overdependence on others or throwing tantrums to gain attention. You should be aware of these problems from the start, and the local coordinator can give you reading materials to help you learn about these areas.

A SPECIAL WORD TO THE PARENTS OF YOUNG PROTEGES

Much has been said to the future advocate in order to prepare him for advocacy, but it is also necessary to give the prospective

protege and you, as his family, some prior information about the program when an interest is first expressed in the local advocacy office.

The protege's family should receive introductory information to read about the advocacy concept and its implementation, and you should see any available audio-visual presentations. You are an important part of the program, and your cooperation with the advocate in record-keeping, and in preparing your child for the relationship will be very important. As the parents of the protege, you should be made aware of all the resources available through the office, and you should know that the advocate has been instructed to work with you, not against you. You should never feel that the advocate is going over your head or behind your back where the protege is concerned. You should be given the opportunity to meet with the advocate and any professionals concerned with your child prior to the actual matching, and if at any time you have a complaint against the advocate or feel that the relationship is harmful to the child, you should go to the local advocacy coordinator at once.

In preparing the protege for an advocate, the parents, houseparents, counselor, social worker, or whoever is concerned, should tell the retarded person that a new friend is coming into his life who will be able to share new experiences with him and help him with any problems he may have. The extent of explanation necessary will, of course, depend on the individual child, and the family or counselor will know the best way in which to handle the situation. It is not necessary to tell him he is a "protege" or to use other technical terms.

WHAT BEING AN ADVOCATE CAN DO FOR YOU

"I feel that the capacity to care is the thing which gives life its deepest significance."

Pablo Casals

Besides gaining the satisfaction that comes from making another human being happy, the advocate knows that he is also helping his protege to live a more enriching life with all his rights intact.

The advocate also gains:

- a better understanding of mental retardation and of handicapped people in general
- the opportunity to make a human contribution outside of his own life-style and occupation
- the knowledge that he is performing a service that cannot be provided by protective agencies today
- a friend

All advocates and the community as a whole may gain a new awareness of the problems encountered by people who have disabilities or are disadvantaged as a result of society's discrimination. Thus, public education increases, leading to positive change in solving many of these dilemmas.

Perhaps the best way of all for you to see just how much an advocate really gains is to let you read first hand what a young woman who served as an advocate had to say about her protege and the program in general:

"I know that I have gained an invaluable amount of awareness, insight, and education from this experience of working with a protege. Getting to know him; organizing and participating in the Halloween party, etc. are learning experiences that could never have been drawn from a textbook.

"It's incredible what one can learn about people just by getting involved. I am no longer apprehensive or frightened of these special individuals—rather now I feel very at ease and comfortable among them . . . they are more similar than they are different. This only infers that they possess exactly the same emotions and needs that all human beings possess.

"It frightens me as well as frustrates me to think how many thousands of mentally retarded are being shut off, hidden and deprived every day—merely because the general public is un-

aware and uneducated. It's so very simple to relate to and communicate with these special people. They are so responsive and starved for any sort of attention that a brief encounter can be extremely rewarding and refreshing.

"I sincerely hope that the Citizen Advocacy program flourishes in the future. I am very strongly convinced that the advocates can benefit just as much as the proteges—if not more —from such a relationship. This is mainly due to the fact that in this busy, frantic, hassled world of ours, such an experience can change one's whole outlook of life almost drastically. It can most certainly make you more thankful for what you do have; it can place your life in its true perspective; it can pull you out of a self-centered selfish syndrome (that we can often fall into when feeling sorry for ourselves, or whatever); and maybe — most importantly, it can brighten the life of one particular and very special person. The program is a lesson in learning as well as a lesson in love. It is a program that can and is helping tremendously to strengthen the bond of human communication, caring and ultimate understanding."

Barbara Falk
Denver University
Denver, Colorado,
December, 1972.

APPENDIX I

Declaration of general and special rights of the mentally retarded

International League of Societies for the Mentally Handicapped

WHEREAS the universal declaration of human rights, adopted by the United Nations, proclaims that all of the human family, without distinction of any kind, have equal and inalienable rights of human dignity and freedom;

WHEREAS the declaration of the rights of the child, adopted by the United Nations, proclaims the rights of the physically, mentally or socially handicapped child to special treatment, education and care required by his particular condition.

Now Therefore

The International League of Societies for the Mentally Handicapped expresses the general and special rights of the mentally retarded as follows:

ARTICLE I

The mentally retarded person has the same basic right as other citizens of the same country and same age.

ARTICLE II

The mentally retarded person has a right to proper medical care and physical restoration and to such education, training, habilitation and guidance as will enable him to develop his ability and potential to the fullest possible extent, no matter how severe his degree of disability. No mentally handicapped person should be deprived of such services by reason of the costs involved.

ARTICLE III

The mentally retarded person has a right to economic security and to a decent standard of living. He has a right to productive work or to other meaningful occupation.

ARTICLE IV

The mentally retarded person has a right to live with his own family or with fosterparents; to participate in all aspects of community life; and to be provided with appropriate leisure time activities. If care in an institution becomes necessary it should be in surroundings and under circumstances as close to normal living as possible.

ARTICLE V

The mentally retarded person has a right to a qualified guardian when this is required to protect his personal well-being and interest. No person rendering direct services to the mentally retarded should also serve as his guardian.

ARTICLE VI

The mentally retarded person has a right to protection from exploitation, abuse and degrading treatment. If accused, he has a right to a fair trial with full recognition being given to his degree of responsibility.

ARTICLE VII

Some mentally retarded persons may be unable due to the severity of their handicap, to exercise for themselves all of their rights in a meaningful way. For others, modification of some or all of these rights is appropriate. The procedure used for modification or denial of rights must contain proper legal safeguards against every form of abuse, must be based on an evaluation of the social capability of the mentally retarded person by qualified experts and must be subject to periodic reviews and to the right of appeal to higher authorities.

ABOVE ALL — THE MENTALLY RETARDED PERSON HAS THE RIGHT TO RESPECT.

October 24, 1968

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